

Making sense of digital media rights: the perspective of young people with cancer in Portugal

Lidia Marôpo, Instituto Politécnico de Setúbal and CICS.NOVA.FCSH/UNL, Portugal

Ana Jorge, Catholic University of Lisbon and CECC, Portugal (Departamento: Faculdade de Ciências Humanas)

This paper proposes a discussion of children's digital rights based on accounts of digital media's experiences by young people under particular circumstances of vulnerability. It draws on a qualitative research on young people with or survivors of cancer, their use of the media and perspectives on their media representation (including news and entertainment in traditional and new media). We conducted focus groups with 13 participants aged 12 to 22, who are still in treatment or had cancer (before the age of 18), recruited through a non-profit association in the field - Acreditar -, in Lisbon and Oporto, Portugal, in 2015.

While the topic of children with cancer is mostly approached by Psychology, we propose a sociocultural approach, which includes contributions from childhood studies (Corsaro, 1997; James and Prout, 1997; Mayall, 2002; Prout, 2005; Almeida, 2009), to investigate the opportunities and constraints posed by digital media to these young people's rights. This means taking young people as active participants in their socialization process and, therefore, capable of elaborating, interpreting and reconstructing the social logics and their experiences, including with the media. In this sense, we were interested in analysing how they make sense of their rights to privacy and participation under the context of the disease, especially when related to social media use.

On the one hand, the participants unanimously reject victimizing representations and several also refuted heroifying portrayals. On the other, different strategies to deal with their image or memory of having had cancer reveal marked singularities and tensions between privacy and self-affirmation: while some teenagers do not share any image of themselves when ill, others consciously manage the use of their image and information about their illness to feel reassured. The participants expressed concern about how to deal with constraints generated by people posting contents about them, even if well intentioned.

Some of the young people claim the right to remove content mentioning them and the right to be forgotten. Others are more acceptive of different digital media visibility (among their social media circles or even public campaigns), provided they have a voice in defining the terms and tone. They see this as opportunity to contribute to a non-stigmatizing representation of the disease. However, particular tensions between adults' and young people's perspectives arose, for example, in families using social networking sites to raise funds, allegedly for treatment, sometimes using the images of very young (sick) children.

Young participants also reported using the internet to search for health information on their condition, which reclaims attention both to their rights to accessible and specialised information and to media and health literacy. The majority of the participants reported an increase in use of different types of media during treatment. Digital media were pointed as an alternative for traditional media, because, in their perspectives, they provide more diverse, quality or age-appropriate content. All this poses both questions of provision of quality content and literacy for children and young people, especially under special vulnerability.